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ABSTRACT

The Camden (NJ) Program for Severely Handicapped Preschool Children, while part of the HCEEP (Handicapped Children Early Education Program) network, is unique in that it reflects the needs and characteristics of the population (mainly Black and Hispanic with a large number below poverty level income) it serves. The staff of the preschool program works to establish trust within the Hispanic community and to provide information concerning the value of early intervention. Program activities include hiring a bilingual parent from the program, hiring several bilingual staff members to interact with Hispanic parents, and conducting cultural awareness activities led by staff or outside consultants. Stressed is the need to consider values and attitudes of the Hispanic culture such as the strong sense of family and the avoidance of eye contact to show respect. (SB)

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WORKING WITH PARENTS OF HISPANIC SEVERELY HANDICAPPED PRESCHOOL CHILDREN

COUNCIL FOR EXCEPTIONAL CHILDREN
CONFERENCE ON THE EXCEPTIONAL BILINGUAL CHILD
February 18, 1981, New Orleans

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Program and Philosophy

The Camden Program for Severely Handicapped Preschool Children (birth through five) is funded by Title VI-B, through the New Jersey Department of Education. In 1980, this program completed its third year as a demonstration project within the Handicapped Children Early Education Program (HCEEP) network with Bureau of Education for the Handicapped (BEH) support. The program incorporates the basic structure of all HCEEP projects; however, its unique and most distinctive features reflect the needs and characteristics of the area it serves. While the project supplies a quality program on an instructional level, it also provides a supportive environment in response to the social and emotional needs of a multi-problem inner city population. It is a program that works because it deals with the realities of urban centers and those stress factors that interfere with parenting and education.

Camden, New Jersey has a school population of approximately 20,000. This population is composed of 65 percent Black, 28 percent

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Hispanic, and seven percent Caucasian.[1] A large number of this population exists on below poverty level income or receives assistance from Public Welfare. The city has many financial problems and much of the industry that flourished in this port city during World War II has diminished or departed. The thriving businesses on the main street are now boarded up, surrounded by poor or inadequate housing.

In this urban center, the problems of implementing and maintaining a program for preschool, severely handicapped children with parental involvement are magnified. Successful programs require that parents and providers work together with patience and sensitivity to provide remediation for the child. Neither the individualized educational program for the child, nor the parent training program can be developed without observing the ecological condition of the total family. Project staff must observe the levels of parental readiness, the family's struggle to maintain basic needs to support life; the importance of building self-esteem in the parent to encourage participation and the specific information and training needs to deal with a particular handicap. The family treatment specialist must establish realistic priority areas with the parent and provide assistance through the coordination of community agencies[2] to help parent and project staff plan cohesively for the family. The treatment of the child in an isolated classroom sense does not answer the global needs of the family unit to permit optimal child progress.

1. Figures taken from Camden City Public School's System Race, National Origin Desegregation Plan, FY1980, James Brown.

2. See Appendix for interagency coordination chart.

Any remediation for the child must be approached with a clear understanding of total family needs so that all participants have reasonable expectations concerning this cooperative effort. When the parent helps to define priorities in an atmosphere that acknowledges and respects cultural and language differences, parental involvement and child progress may result. Techniques and methodologies mean very little to the family whose concern lies in securing adequate housing, food, and clothing.

The child treatment component of a full service program must be integrated carefully and sequentially as parent progress occurs to maximize growth potential for all. The underlying theme of the program is orchestrated by the family treatment specialist who works at a very basic "gut" level with the family. In the meantime the staff, consultants and medical community observe the child and gather information for the production of a multi-disciplinary IEP. A program is provided on the site four or five half-days per week, or in the home when necessary. The program philosophy is cognitive-developmental with behavioral techniques used when needed. The youngsters in the group present a variety of severe deficits in the motor, communication, intellectual or emotional areas. Frequently, the child may have serious health problems or seizure activity. When ever possible, one-to-one intervention is provided through teaching staff, aides, CETA workers, high school students and parent volunteers. This is especially helpful with the infant population where individual attention is almost a necessity.

The older preschool children have many group socialization activities in addition to the period of individual attention for all youngsters, data collection is done on specific objectives so that ongoing program monitoring is provided. The staff also assesses child growth twice a year, using the Early Learning Accomplishment Profile (E-LAP) and Learning Accomplishment Profile (LAP). Many daily activities are taken from the Nisonger Infant Stimulation Curriculum or provided through the consultants in physical therapy, speech pathology and feeding. Bilingual intervention is available whenever needed with staff assigned to provide appropriate intervention.

Cultural awareness must begin with the individual's recognition of his own beliefs and biases. From this initial step, staff persons can be helped to develop a sensitivity to other cultures. The inclusion of preservice course work into existing teacher training programs will help somewhat, but a better vehicle for learning is the experience of another culture. In order to do this, it is necessary to listen, observe and give thought to the culturally different factors that must be addressed. Too often people dismiss differences as unimportant because they have no meaning for them. It is necessary to remember that a culture is the manner in which one responds to the environment in physical, social and spiritual terms. "Culture is composed of habitual patterns of behavior that are characteristic of a group of people and transmitted from one generation to another..." (Henderson, 1980, p.598).

Parents representing other ethnic groups have a desperate need to be understood. This can represent a time-consuming task for staff, necessitating patience and concentration.

The reluctance and hesitation of culturally diverse families must not be interpreted as disinterest. It must be recognized for what it is, the result of social isolation, inability to communicate in English, and the subsequent loss of self-esteem often associated with the birth of a handicapped child (Marion 1980). It becomes the job of the staff to inform parents of their rights; to solicit and value their input in the planning conference; to break down the atmosphere that connotes authority and to help parents toward interaction with staff and peers. Using parents as resources for cultural sensitivity workshops and staff training certainly helps to enhance self-image and provides a valuable source of information. Topics such as nutrition, health, sex roles, religious beliefs and many more can be presented by parents to staff. Opportunities for working, sharing and socializing together must be included to help break down barriers. The basic need to belong is even more important to one who has learned to view himself as undesirable (Marion, 1980). Clear communication through body language and verbal means helps to engender the supportive atmosphere needed to elicit parent participation. It must be observed that a conflice between cultural patterns at home and classroom expectations may exist which may interfere with skill acquisition (Chan and Rueda, 1979). Values must be considered when developing curriculum and not only those of the dominant society (Alamanza and Mosley, 1980). The growing trend toward the addition of a multicultural education component in teacher training programs will be a helpful step toward awareness for beginning educators. However, much of the attitudinal change must be done on a personal level and is dependent upon

the individual's ability to accept the viewpoint of another.

Parent/Program Communication Process

The staff of the preschool program for severely handicapped feels a special satisfaction because of the numerous referrals and enthusiastic involvement of the Hispanic families in Camden. At first, for many cultural and social reasons, Hispanics were somewhat hesitant to participate. It was necessary to establish trust with the community and to provide information concerning the value of intervention. The addition of a bilingual parent from the program (family liaison worker) to the staff proved an effective measure in opening communication. The hiring of several bilingual staff members (including a bus driver) who regularly interact with Hispanic parents strengthened program desirability. Access to Hispanic staff persons has helped other staff members to work with language and cultural differences. Hispanic parents feel comfortable and participate regularly, sometimes leading group sessions. Cultural awareness activities led by staff or outside consultants have also helped to sensitize staff to the needs and expectations of the Hispanic population. Parent particiaption during group meetings has intrinsic value both for the parent and for staff. The family treatment specialist serves as facilitator often with the help of an Hispanic staff member or parent.

The family treatment specialist also assists the parent in seeking information and agencies which can help. It is essential that any session with the Spanish-speaking parent have an interpretor available so that important personal information is under-

stood. Thus, Hispanic parents who may be intimidated by authority figures who appear to equate the inability to speak English with inferior status, are able to communicate fully. In this atmosphere, concerns regarding handicapping conditions and remediation may have immediate, effective responses. Important developmental milestones, medical and prenatal factors can be a part of the case record with the necessary parental involvement for a good IEP. At the same time, questions regarding handicaps can be addressed and referrals made to appropriate agencies for the additional services needed. A request for bilingual services is made prior to project staff evaluations and outside agency assistance. This helps to ease the parent's pathway through the maze of the agency network. The anxiety a parent experiences in anticipation of this difficult process is somewhat alleviated with the addition of bilingual staff. Facilitating communication is an important requirement for program success and must always be considered in any group or individual consultation activity. A full service program must consider this aspect at every level to prevent the feelings of suspicion and mistrust arising from poor communication.

Cultural Factors

Consideration and understanding must be given to the values and attitudes attached to the culture of the Hispanic parents of severely handicapped children in this program. The beliefs, myths and patterns of behaving within the culture are fostered, nurtured and transmitted from one generation to the next. In the Hispanic culture these are very strong because they continue to be reinforced constantly.

The initial acceptance of a severely handicapped child in the

Hispanic home is a very difficult experience with certain religious beliefs involved. There are parents who view this child as "their cross to bear" and think that God is testing their endurance or punishing them for past sins. In either case, the parent assumes a fatalistic view of the child's potential. Historically, these handicapped youngsters may have been isolated in a room and rarely provided with stimulation or medical aid because it was accepted that nothing more could be done. The parents role was one of caretaking and protecting while the developmental potential remained unchallenged.

Hispanics have a very strong sense of family, which includes the grandparents, aunts, uncles, or "extended family". There is much nurturing and protectiveness provided to the child which makes sending him to the large, impersonal environment of the school more difficult. The handicapped child is felt to be the responsibility of the family unit, especially during the early years. The project staff must reassure the family through communication and interest that their child will be safe away from home.

Another factor which must be considered by the program is the different learning styles among cultures. Behaviors which the teacher may find unacceptable may be culturally appropriate. These behaviors, (among both parents and children) have been culturally modeled and perpetuated through the generations. An action such as lowering the head and avoiding eye contact when spoken to or reprimanded, is a sign of respect. Embarrassment or shyness may be interpreted by the staff as nonparticipation or resistance. Touching or closeness may be grossly misunderstood by the Hispanic family because of the strict rules of conduct

the culture requires.

In the preschool classroom a number of Hispanic parents were opposed to the babies being undressed or changed with those of the opposite sex. They expressed objection to the male aide assisting the girls on the potty or diapering the female infants. It was necessary for the staff to accept this cultural value in order to regain the trust of the families. At the same time, the staff had difficulty involving the Hispanic fathers in the classroom activities of their handicapped children, because of their deep-rooted attitudes about the paternal role in childrearing, especially with the handicapped child. All of these factors need to be considered so that productive and effective parental involvement can take place.

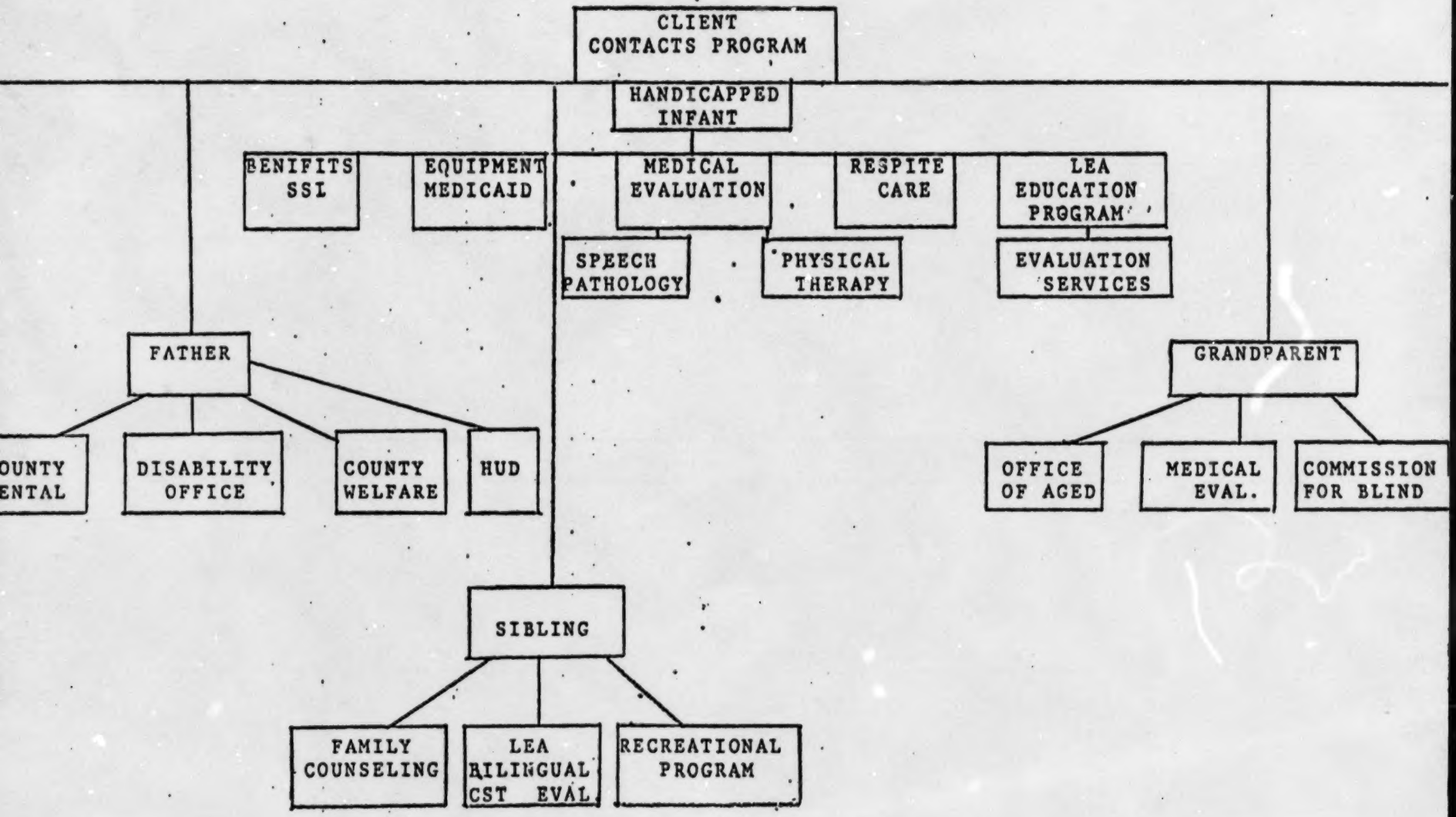
The school may loom as somewhat frightening for Hispanic parents. They traditionally view it as a place that is off limits, yet they are required to turn their children over to school staff with blind faith. Part of the fear of entering stems from the feeling of being different or an outsider. It is crucial to seek the parents out and to encourage their involvement. Once they gain self-assurance and are able to communicate with staff through a bilingual staff member, much of the fear will subside. In this way, the cooperation and input that is so essential may be possible and the program gains a valuable resource. Not only does the parent provide information and assistance but eventually will be able to understand and assist in the training activities of the handicapped child.

The initial time and patience expended to involve the Hispanic parent pays off for all concerned. Cultural plurality in

the classroom is a necessary ingredient for a successful program in Camden. Educators must learn to be advocates for the culturally diverse, not as an act of benevolence but as an essential professional prerequisite to the provision of a valid program.

CHART A

COMPREHENSIVE SERVICE COORDINATION FOR FAMILY OF HANDICAPPED INFANT



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